GRANDPARENTS AND THEIR GRANDCHILDREN WITH AUTISM SPECTRUM DISORDER: BUILDING BRIDGES THROUGH TECHNOLOGY

by

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ABSTRACT

Grandparents of grandchildren with Autism Spectrum Disorder (ASD) remain an under researched population. This research provides grandparents a voice concerning the experience of their grandchildren with ASD in workshops that taught them the use of the 3D Google SketchUp™ software. The workshops focused on the computer strengths of the participating children. Six grandparents participated in two focus groups. Videotapes from the focus groups were transcribed verbatim and coded. Two key themes were identified from the data: reframing expectations and building communication bridges through shared interests. Grandparents perceived that their grandchildren learned technological skills and had a positive experience, which gave them hope for future educational and employment opportunities for these grandchildren. The grandparents perceived that the shared interests in the computer program augmented communication opportunities between themselves and their grandchildren, and with other grandparents of children with ASD. This paper addresses the challenges children with ASD and their families experience and explores from the grandparent's viewpoint the potential benefits of social engagement around technology.

To the grandparents who shared their hearts and thoughts with me. And to my mother and father, my children's grandparents, who have always encouraged and supported me and my children.

CONTENTS

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INTRODUCTION

Changing demographics have resulted in the potential for greater intergenerational relationships between a grandparent and a grandchild. At the same time, the incidence of Autism Spectrum Disorder (ASD) has increased dramatically, thereby increasing the number of grandparents with a grandchild with Autism Spectrum Disorder. Little research has examined how the grandparent-grandchild relationship is affected by having a grandchild with Autism Spectrum Disorder. The families of a child with ASD face many social, emotional and possibly financial challenges. Positive experiences and supportive environments for children with ASD and their families may feel limited. An actively involved and supportive grandparent of a grandchild with ASD can be invaluable.

This research uses a qualitative study method to investigate grandparents' perceptions of their grandchildren with ASD's experience of participating in Google SketchUp™ workshops

LITERATURE REVIEW

Changes in demographics

While life expectancy has increased, fertility rates in America have decreased (Shrestha, & Heisler, 2011). The result is that the number of generations within each family is greater, and the number of people in each generation is less. With longer human life expectancy in industrialized societies, the opportunity for grandparents to play a significant role in the lives of their grandchildren has also expanded. In industrialized societies the typical grandparent is young (relative to life expectancy) and healthy (Manton, Gu, & Lowrimore, 2008). Not only are more people living to experience the role of grandparent, but the length of time that they spend in this role is also extended (Hodgson, 1998). As these changes alter the nature of relationships between generations, the meaning ascribed to the role of grandparent may also be modified (Hayslip, Henderson, & Shore, 2003).

The role of grandparents today is not clearly defined and is fraught with ambiguity. Many grandparents find themselves trying to find a reasonable balance of support and involvement in their children and grandchildren's lives while maintaining a degree of independence for themselves. Mason, May, and Clarke (2007) describe it as, "the ambivalence between being there and not interfering" (p.687). Grandparent involvement can be viewed on a continuum from no contact with grandchildren at one

end, to grandparents being sole caregivers for their grandchildren at the other. For grandparents who do not have the responsibility of being sole caregivers for their grandchildren, involvement ranges from being actively involved in planning and carrying out activities on a daily or weekly basis to being uninvolved, with no contact.

As a result of population aging, an increasing number of grandparents are available in families to provide functional support such as perform housekeeping chores and assisting in raising grandchildren (Amparo Cruz-Saco & Zelenev, 2010). Grandparents may provide adaptive resources for parents of a child with Autism Spectrum Disorder, ensuring the integrity of the family (Silverstein, Giarrusso & Bengtson, 2003). The emotional, functional, and financial support that a grandparent could provide may help buffer the increased stress having a child with ASD places on the family system. This study examines the relationship between actively involved grandparents whose grandchildren with Autism Spectrum Disorder participated in SketchUp™ computer workshops at the University of Utah.

SketchUp™ is a 3D modeling program designed by Google for architects, civil engineers, film makers, game developers and other related professionals. Google employees received calls from SketchUp™ users expressing how their children with Autism Spectrum Disorder are drawn to this graphic design program. Given the visual-spatial strengths of some individuals with ASD, computer programs like SketchUp™ may be especially appealing (Guercio, 2009).

As a result, Google created Project Spectrum to give people with autism the opportunity to express their creativity and develop a life skill using Google SketchUp™ 3D modeling software. Google contacted faculty at the University of Utah, who provided public lectures and subsequently workshops for children with ASD using the SketchUp™ software.

Autism Spectrum Disorders

Autism spectrum disorders (ASD) are neurodevelopmental disorders characterized by impaired social interactions, deficits in verbal and nonverbal communication, and repetitive behaviors or unusual or severely limited interests (American Psychiatric Association, 2000). Autism Spectrum Disorders (ASD) is defined by a set of behaviors that can range from mild to severe; therefore children on the autism spectrum are not a homogenous group (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). Each child with ASD will display communication, social, and behavioral patterns that are individual, but fit into the overall diagnosis of ASD.

ASD occurs in all racial, ethnic, and socioeconomic groups, with boys four times more likely to be affected than girls (CDC, 2010). It is typically recognized within the first three years of life. ASD affects a child's ability to communicate and interact with others. A child's autism diagnosis affects every member of the family. Researchers Seltzer, Krauss, Orsmond and Vestal (2000) state, "Few disorders can pose a greater threat to the well-being of families than autism; as a result of its lifelong emotional, social, and financial costs" (p. 272). For the parent, helping their child with ASD often becomes their central focus, placing many of their resources of time and money towards providing treatment and interventions. Although there is no proven cure for autism, the goal of treatment is to improve the overall functional status of the child. This is achieved by promoting the development of communication, social, adaptive, and behavioral skills, educational attainment, as well as by lessening maladaptive and repetitive behaviors (Committee on Children with Disabilities, 2001). The added time, attention, and financial demands for treatment and interventions add stress and can strain family relationships. Tehee, Honan and Hevey (2009), in their study of

the factors that contribute to the stress for parents of children with ASD, reported that the highest sources of stress were challenging and antisocial behaviors, concern for the future, education, and attaining support and services. They also found that respite service and family support are among the highest facilitators of stress relief.

Hillman (2007) states, "a grandparent has a 1 in 166 chance of becoming a grandparent to a child with an autism spectrum disorder" (p.513). For the grandparent, who anticipated hugs and kisses, disappointment and worry for both their child and grandchild becomes a reality (Bloch & Weinstein, 2010). Margetts, Le Couteur and Croom (2006), in their study of the experience of being a grandparent to a grandchild with ASD, describe it as the "double burden of caring for two younger generations" (p. 569). The grandparents worry for the well-being of their child and their grandchild. Woodbridge, Buys and Miller (2009) explain it as "Double grief: sadness for what might have been for both their child and their grandchild" (p. 37).

The grandparents' reaction and interactions with their child, their son or daughter-in-law, their healthy grandchildren, and their grandchild with the disability impacts the family dynamics and the family's adaptation (Seligman, 1991). Many studies have found that higher levels of received informal social support from friends and family members is associated with lower parental stress, greater feelings of parental empowerment, and higher levels of marital satisfaction (Hastings, Allen, McDermott, & Still, 2002; Keller & Honig, 2004; Saloviita, Italinna, & Leinonen, 2003; White & Hastings, 2004). The resources that a grandparent can bring to the family of a child with ASD include emotional support to help the entire family cope, instrumental support in the form of hands on assistance and financial support.

Family Systems Theory

Changing demographic trends mean that today men and women could spend many years actively grandparenting (Harper and Levin, 2005). Yet, intergenerational relationships between a grandparent and grandchild do not exist in a vacuum; rather this relationship is a function of the family network (Uhlenberg & Hamill, 1998). The family systems theory introduced by Dr. Murray Bowen (1954) suggests that individuals cannot be understood in isolation from one another, but rather as a part of their family. The family systems theory is a theory of human behavior that views the family as an emotional unit and uses systems to describe the complex interactions in the family unit. It asserts that it is inherent in the nature of a family, that its members are connected emotionally. Family members affect one another's thoughts, feelings, and actions. Family members solicit one another's attention, approval, and support and react to one another's needs, expectations, and distress. It is both the connectedness and reactivity that make the functioning of family members interdependent. A change in one person's functioning is predictably followed by reciprocal changes in the functioning of others. The family systems theory contends that families are systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system. How each member of the family relates, communicates and behaves is critical to understanding the whole family (Wright & Leahey, 2005).

As a result of the child's disability, all family members and the family system itself will need to make significant adjustments. A child's disability will have implications for family life as a whole. The family may face constraints of recreation and leisure activities, social engagements, and financial concerns (Blachera, Neeceb, & Paczkowskib, 2005; Bloch & Weinstein, 2010). Daily activities and social interactions may center on the needs of the

child with ASD. Appointments and therapeutic schedules and interventions can demand time and attention, limiting moments and energy spent with other family members. Having a child with ASD may also be emotionally exhausting for parents and family.

. A family systems approach suggests that having a child with autism spectrum disorders (ASD) affects all members of the nuclear and extended family. One of the ways that families maintain homeostasis is through the roles that different family members play. A family role is the understood place in the family system, where expected patterns of behavior and emotion are performed by family members. In a family with a child with ASD, often the role of caring for this child falls predominantly upon the mother. Gupta and Singhal (2005) examined stress levels and coping strategies used in families with a child with autism, and found mothers of children with autism often experience low parenting competence, less marital satisfaction, and family adaptability. The mothers of a child with ASD report significant levels of chronic stress and fatigue. The mothers are also the parent who is most likely to be held responsible for their child's behavior; both by their husbands and by people outside the family (Gupta & Singhal, 2005). Fathers in the families of a child with ASD were less involved with physical care and domestic tasks and more with providing support. Being the sibling of a brother or sister on the autism spectrum can be challenging. Siblings may have to assume greater responsibilities in the family and may feel that their parents perceive their needs as being secondary, with more time and attention given to the child with autism. Studies indicate that having a child with autism impacts most aspects of family life, including the activities of daily living, housekeeping, finances, the emotional and mental health of parents, and their marital relationship. Poor sibling relationships and relationships with extended family, friends and neighbors, as well as constraints on family recreation and

leisure activities are additional family outcomes (Sander & Morgan, 1997). Raising a child with autism is an all-encompassing task that is often exhausting and isolating, and families accommodate in certain ways by organizing the environment around them into daily routines. A grandparent's support can help sustain the family system.

The parents of the child with ASD and the parents'relationship with the grandparents have a direct effect on the grandparent-grandchild relationship. Indeed, the parents have been referred to as the 'gate keepers' to this relationship, with the amount and quality of the grandparent-grandchild relationship being dependent on the grandparent-parent relationship (Rossi & Rossi, 1990). The grandparent-grandchild relationship is closer when the grandchild's parents and grandparents get along (McKay & Caverly, 2004). Interactions within the family system are not static, but evolve and change over time. For the family of a child with disabilities, the grandparent's role and relationship with different members may adapt in response to varying levels of stress and coping ability. With the diagnosis of ASD the grandparents may provide emotional support and nurturance for the parents and extend functional and financial support as well. A grandparent can give unconditional love and companionship to a grandchild with disabilities as the relationship develops over the years and help provide balance within the entire family system (Kornhaber, 2003; Kropf & Burnette, 2003; Mueller & Elder, 2003).

For families with a disabled child studies indicate that relationship factors between the parent and the grandparent predict grandparent involvement much more than the child's disability does (Gardner, Scherman, Efthimiadis, & Schultz, 2004; Katz & Kessel, 2002). Raising a child with disabilities involves balancing a number of challenges, including seeking and gaining support (Canary, 2008). For the families of children with disabilities,

grandparents are increasingly providing care and support (Neely-Barnes & Dia, 2008). The present study examines the grandparents' relationship with their grandchild with ASD from the family systems perspective.

The Grandparent-Grandchild Relationship

The grandparent-grandchild relationship is an important one, described by psychiatrist Arthur Kornhaber (2003) as being second only in importance to the parent-child relationship. The value of this relationship to both the grandparent and the grandchild is becoming increasingly recognized (Crosnoe & Elder, 2002: Soliz, Lin, Anderson & Harwood, 2006). The emotional attachment between grandparents and grandchildren has been described as unique in that the relationship is exempt from the psycho-emotional intensity and the responsibility that exists in parent-child relationship (Kornhaber, 2003). The love, nurturance, and acceptance which grandchildren have found in the grandparent-grandchild relationship "confers a natural form of social immunity on children that they cannot get from any other person or institution" (Kornhaber & Woodward, 1981, p. xxi). Research has demonstrated that the grandparent-grandchild relationship is valuable for the grandparent (Thomas, 1990) and for the grandchild (Brussoni & Boon, 1998). Tomlin (1998) stated that the grandparent-grandchild relationship was important to the emotional development and self-esteem of the grandchild. For many grandparents their relationship with their grandchild is a source of pride (Harwood & Lin, 2000) and something that "keeps them young" (Harwood, McKee & Lin, 2000). The unique bond formed through the grandparent-grandchild relationship can function as a family resource for the entire family

system. For a grandchild with Autism Spectrum Disorder this relationship may be even more critical.

Communication is important to all of us, but for many individuals with ASD, establishing an effective means of communication is a major challenge. Difficulties in verbal and nonverbal communication are a core challenge in ASD. Harwood (2000), in his study of communicative predictors of solidarity in the grandparent-grandchild relationship, found the most consistent predictor of solidarity to be the perceptions of the level of accommodation made to them. Grandparents and grandchildren who felt the other was complimenting them, showing affection and respect, and being attentive and supportive of their personal thoughts and feelings had stronger relationships. Many children with ASD have difficulty interpreting and managing their emotions (Attwood, 2000), in addition to decoding the emotions that others can read easily on human faces (Baron-Cohen & Wheelwright, 2004). A grandchild with ASD, who has difficulty with social interactions, and interpreting social cues and communicating, could negatively affect the grandparent grandchild relationship.

Fingerman (1998) suggests that grand parenting needs to be considered as a series of relationships and not as an overall role in an individual's life. She explains that a grandchild who is special due to personal problems, one who the grandparent worries about, benefits from a high quality intergenerational grandparent-grandchild relationship. For a grandchild with ASD this relationship may be substantial. Likewise, grandparents may derive benefits from grandchildren who are distinct by virtue of their achievements, shared interests, or attributes. Alternately, a grandchild with special needs, who has inflexible difficulties or who exhibits behavioral problems may discourage grandparent interactions and involvement (Fingerman, 1998). Lee and Gardner (2010) explain that grandparents often assume

additional roles that include unique involvement and support in families with children with disabilities. Given the family's interconnected relationships outlined in the family systems theory, it is likely that grandparents may recalibrate family contributions to enhance the social, emotional and developmental requirements of grandchildren with greater needs (Cooksey, Menaghan, & Jekielek, 1997).

Communication Challenges, Building on Strengths

Children with ASD are deficient in social and communication skills which can affect interactions and the establishment of relationships with family, peers, and other adults (Rao, Beidel & Murray, 2008). Their social and communicative deficits include inadequate use of eye contact, difficulty interpreting both verbal and nonverbal social cues, and inappropriate emotional responses (Weiss & Harris, 2001). These limitations, as well as difficulties in understanding the perspective of others, can make the establishment of a satisfying grandparent-grandchild relationship challenging.

In recent years many computer programs and technology have been directed at teaching social and communication skills to children with ASD (Baron-Cohen, Golan, Wheelwright, & Hill, 2004; Bolte et al., 2010; Mitchell, Parsons, & Leonard, 2007). For these children, who often experience discomfort in social settings, computers provide a predictable, controlled environment in which they can work at their own pace and ability level (Charlop-Christy, Le, & Freeman, 2000; Golan & Baron-Cohen, 2006). Likewise many of these children have strong visual spatial skills and are adept at computer use (Rayner, Denholm & Sigafoos, 2009). The 3D computer program, SketchUp™, used in this study's workshops with children with ASD played to these strengths. Shane and Albert (2008)

explain that using computers as a teaching method for children with ASD is both appropriate and motivating. SketchUp™ is not a communication or social skills teaching program, yet the SketchUp™ program is engaging, as it may capitalize on the strengths of some children with ASD.

Peer Support

The grandparents of a grandchild with ASD often have the added stress of not having a peer group with whom to share their feelings and problems (Jendrik, 1993; Minkler, Driver, Roe & Bedeian, 1993). A feeling of isolation within the community is commonly expressed by the family members of a child with disabilities (Martin & Colbert, 1997). Research on peer support groups shows that they provide an arena within which participants can both provide and receive support (most often emotional support). Support groups also provide members an opportunity to develop friendships and build lasting social networks (Maton, 1988; Rappaport, 1985). Woodbridge et al. (2009) studied the emotional journey for grandparents of a grandchild with a disability; she concluded that grandparents, as well as parents, need support to help them process their emotions and to develop ongoing strategies to cope with their situation. The focus groups used in this study provided such an opportunity.

Rationale for Research

This research sought to examine, from the grandparents' perspective, their grandchild's experience with the SketchUp™ workshops. The present study used a qualitative research design to examine the thoughts, feelings, and perceptions of grandparents

of their grandson's experience with the SketchUp™ program. Qualitative research design is holistic and in this study looked at the larger picture of the grandparents' relationship with their grandchild in the context of the family and the community in which they live (Denzin & Lincoln, 2000). Qualitative research is not designed to test specific hypotheses, but to look for the meaning or perspective from the participants in the study. Qualitative research methods are valuable in providing rich descriptions. The methods chosen provided detailed explanations from the grandparents' perspective. They illuminate the experience and the interpretation of the experience by family members. Denzin (1989) explained the information gathered from qualitative research design as, 'It presents detail, context, emotion and the webs of social relationships that join persons to one another' (p.83). Qualitative research design is also notable in giving a voice to those whose views are rarely heard (Sofaer, 2002). Grandparents' of grandchildren with ASD are often overlooked in research and thus the qualitative design allowed the reader a glimpse of the lived experience of this small group of study participants (Howell Major & Savin-Baden, 2010). The focus groups enabled researchers to access substantive content from verbally expressed views, opinions, experiences, and attitudes (Berg, 1998).

METHODS

In qualitative research methods the experience and voice are represented from the standpoint of those studied (Gubrium, 1992). The focus groups enabled the participants to relate their experiences and perspectives among peers who shared the common frame of experience, having a grandchild with ASD participating in the SketchUp™ workshops. Group members commented on each other's point of view and explored this lived experience. This "insider perspective" adds to the richness of what we know about the experiences of grandparents.

IRB Exemption

The University of Utah Institutional Review Board (IRB) deemed the collection of data from the grandparents focus groups as exempt, because the research was part of education instructional strategies, and an evaluation of these strategies by the grandparents. Respect of privacy and assurance of confidentiality was maintained. Only team members had access to the taped and transcribed documents, and hard copies were kept locked in the team office. Rigorous procedures were used to protect confidentiality of study data and identity of subjects. Only initials were used on the transcribed documents to enable researchers to identify the speaker. Real names are not used in this document and permission to quote the grandparents' was acquired.

Participants

Initially a community seminar demonstrating the uses of SketchUp™, was sponsored by the University of Utah and Google. From a list of interested seminar participants, seven boys participated in a five session SketchUp™ workshop, promoted specifically for children with ASD. A convenience sample of grandparents whose grandchildren with ASD were participating in the workshops, participated in the current study. This sampling technique is useful in documenting the quality of the relationship between these grandparents and their grandchildren with ASD. Six grandparents (four grandmothers and two grandfathers) voluntarily participated in two focus groups. These six grandparents represented four families of the seven children participating in the SketchUp™ workshops. The grandmothers' ages were 54, 68, 69 and 81 years. The grandfathers' ages were 56 and 70 years. Two grandparents had high school as their highest level of education, one had some college, two a bachelor's degree, and one had a master's degree. Their income range was from $60,000 to $130,000. All were married, and four were still employed. All but one were maternal grandparents to the grandchild with ASD.

Intervention Program

The design of the SketchUp™ workshops in which the children with ASD participated and the physical environment is noteworthy. The structure of the workshops encouraged social interaction among the children, with their school peers and with family members. At the end of each session the children shared their SketchUp™ creations in presentations on a large screen to each other, and answered questions about them. Family members were invited to attend these presentations. The children were encouraged to help

each other throughout the workshops, be respectful during presentations and ask appropriate questions. At the end of the five week SketchUp™ program, family and friends were invited to a social celebration where the participants presented one of their SketchUp™ creations to the entire audience. The SketchUp™ workshop team also organized with the participants' teachers to have them present their SketchUp™ designs to their classmates at their schools.

The built environment of the computer lab had the computers set up in two rows, such that the children worked back to back with and beside someone. This enabled the children to easily turn to see what each was designing and they often looked at and commented on each other's creations.

Family members were encouraged to attend the children's presentations and siblings often attended the workshops with their brothers. The small number of participants helped everyone become acquainted and comfortable. The inclusion of family members, presentations and open door policy encouraged discussions.

Procedure

Two focus groups were conducted. The first focus group was held the week after the fall five week workshop ended and the second follow-up focus group occurred three months later. Each focus group session, lasting approximately 90 minutes, consisted of broad, open-ended questions that examined the interactions and activities grandparents share with their grandchildren and also the grandparents' feelings and perspectives about their grandchild's participation in the SketchUp™ program. We also allowed for group directed questions and discussions. Focus groups enable researchers to access substantive content of verbally expressed views, opinions, experiences and attitudes (Berg, 1998). The focus groups were

held on campus at the University of Utah and moderated by two of the of the research team members. The focus group discussions were audio recorded and videotaped to accurately capture the grandparents' discussion and responses. The recorded focus groups were transcribed verbatim and analyzed.

Data Analysis

Both line by line coding and focused coding methods were used to tease out key points from the focus group verbatim texts (Charmaz, 2006). Each team member read the transcriptions and noted and recorded relevant text segments and ideas. Using grounded theory methods, we read and re-read, and coded the data. Observations of main ideas were discussed at team meetings. Through multiple meetings to discuss and chart findings, significant codes were synthesized into common concepts. Common concepts were then identified by overarching key interpretive themes. Inductive coding allowed understanding to emerge from the close study of the verbatim transcribed focus group recordings (Bernard, 2000).

The dependability of the findings was addressed by having multiple researchers analyze the data. The research team consisted of nine individuals with different backgrounds: a developmental psychologist, an early childhood educator, an occupational therapist, a gerontologist, a special education teacher, three social science graduate students, and an undergraduate student in communication. Member checking is commonly used to ensure the validity of themes emerging from qualitative analysis (Lincoln & Guba, 1985). Themes were further verified with the grandparents in a second follow-up focus group.

RESULTS

The results of this study focused on the grandparents' perceptions of their grandson's participation in the SketchUp™ workshops. Qualitative research is described as iterative in its process, with the ability to be flexible and shift directions as salient information is gleaned (Marshall & Rossman, 1995; Mason 1996). The two key themes that emerged were 1) reframed expectations, and 2) building communication bridges through shared interests. Direct quotes from the transcripts will be used to illustrate how these emergent themes were identified.

The themes indicate that, through their participation in the focus groups and their grandson's participation in the SketchUp™ workshops, the grandparents were able to reevaluate and modify their expectations for their grandchildren, as well as identify the potential benefits of computer technology for these grandchildren. The grandparents' experience indicates the importance of hope, focusing on strengths, and of seeing the potential and possibilities for their grandchildren's future. The grandparents expressed their belief that the computer skills their grandchildren developed and the experiences they had in the SketchUp™ workshops facilitated an opportunity for the grandchildren to communicate with others with common interests and abilities. The focus groups emphasized the value of support from shared experience for the grandparents, many of whom, for the first time, were able to express and verbalize their feelings, concerns, and joy with other grandparents of grandchildren with ASD.

Key Theme: Reframing Expectations

The reframing of expectations theme emerged from four strong, recurrent concepts expressed by grandparents: previous failures, limited social skills, building on strengths, and positive experiences through workshops (see Figure 1).

Previous failures

The grandparents described that previously their grandchildren had experienced more defeats than successes in community activity participation. “They [his parents] have tried everything and he just decides it’s not for him,” stated one grandmother. Another grandmother explained, “He was interested in playing soccer, playing tennis and so forth, but his skills… he’s not athletic at all.” One grandfather shared that his grandson, “does not get the concept of the overall game. He can run up and down the court, he can catch the ball, but to go beyond that, he doesn’t seem to figure it out.” Most extracurricular activities that their grandchildren had previously participated in were viewed as being less than successful. Finding an interactive leisure activity that children with ASD enjoy and that encourages development and communication can be challenging. Both the children and their parents experienced frustration and disappointment from many activities in which they had participated in the past. A grandmother stated that her grandson’s interest in other activities he tried “had been short lived.” A grandfather explained, “He has an understanding of the game, but he would rather just not participate.”

Limited social skills

For some of the grandchildren with ASD developing and maintaining friendships was difficult. One grandfather summed it up well with, “Having friends has always been a little ‘iffy’. Social interactions, friendships and other relationships for children with ASD are vital to optimal educational and social development (Cadigan et al, 2006). The grandparents expressed the genuine friendships they believe their grandchildren developed in SketchUp™ workshops, both with the other children and with the adult mentor. At the second focus group one grandmother explained to another that her grandson was very excited to interact with the other woman’s grandson. She explained that he had expressed himself in a greeting and asked if the other boy missed him. Another informant commenting on watching her grandson’s class presentation of SketchUp™ said, “He [her grandson] learned how to defer to Steve [an adult]. He would defer when he couldn’t answer and he needed to ask. He did it appropriately.” A grandfather shared after attending his grandson’s classroom presentation, “The bell rang and they went out to recess and he had a little friend with him. He was playing around, that’s unusual.”

Building on strengths

The grandparents were adamantly against labeling their grandchildren and commented often on their grandchildren’s strengths. Some were excellent readers, many had focused interests, and all of them were proficient in computer skills. “Computer skills, he is just a whiz at computers,” remarked one grandmother. Referring to video games that their grandchildren play, a grandmother commented, “It’s amazing how they are all into that” and a grandfather added, “And it seems to suit the autism.” A grandmother and grandfather

explained how playing computer games had helped their grandson to read, "You have to read some instructions to get somewhere else. So that prompted him. I used to have to help him with the words, now he just takes off" All grandparents agreed when one grandmother stated, "They all seem to gravitate to this medium [computers]." The SketchUp™ workshops were perceived to reinforce the observed computer strengths of the grandchildren. The grandparents recognized the potential value of computer technology, such as the SketchUp™ program and the skills that their grandchildren were learning as beneficial for their grandchildren's future.

Positive experiences through workshop participation

The grandparents overwhelmingly expressed the successes and recognized the potentials they perceived their grandchildren with ASD to have had from their participation in the SketchUp™ workshops. "I've wondered if participating in this program has built in some real confidence that he didn't have before. He's happier. I don't know what else to attribute it to," said one grandmother. They expressed observing their grandchildren's enthusiasm for the program and perceived increased self-esteem and confidence in their grandchildren. One grandmother said, "His brothers are in soccer, but this is his idea of fabulous, the SketchUp™. He just absolutely loves this." Another grandmother talking about her grandson's experience stated, "He is very excited about it [SketchUp™], this has been quite a highlight for him." The grandparents said that they witnessed improved social skills watching their grandchild's presentations and interactions with peers and said the computer skills that their grandchildren developed gave them a sense of hope for future educational and employment opportunities. "I've seen a great deal of confidence from the SketchUp™,

because he knew how to do this" said a grandfather. A grandmother added, "This program has evidently been something that he [her grandson] has really taken to and I think that it has given him a great deal of esteem."

In the first focus group with the grandparents, concerns about the future for their grandchildren with ASD were voiced. "But then even if he achieves everything [as far as education], what about employment? What will he do?" This same grandparent, whose grandson was graduating from high school, expressed enthusiastically in the second focus group, that he would be attending an art institute the following year for animation, or game design. She said when asked about her previous concern for her grandson's future, "Now I am much more comfortable, it's what he wants to do."

Key Theme: Building Communication Bridges through Shared Interests

The building of communication bridges through shared interests emerged from two concepts: social engagement around technology and peer support through focus groups (See Figure 2).

Social engagement around technology

These actively involved grandparents were interested and engaged with their grandchildren with ASD on a weekly, if not daily basis. When asked, what does grandparenting mean to you? One grandfather replied, "It means being part of a grandchild's life." Another grandmother described her perspective on her relationship with her grandson as she explained, "I retired and so at that time I decided I would do what he [her grandson with ASD] wanted to do. So, I decided to make my goal, his goal." One grandmother had

been the driving force to seek out this program for her grandson; many provided the transportation to and from workshops, and all attended their grandchildren's presentations. These grandparents appreciated and acknowledged the draw computers had on their grandchildren, but did not share their enthusiasm for using them. This was well verbalized by a participant with, "I am not at all captivated by technology." All expressed an effort to learn, to be able to share this as part of their relationship. As vocalized by a grandmother, "So if anything, I am trying to get better at the computer at his request [Her grandson with ASD]". The grandparents perceived that the technology provided an opportunity to engage their grandchild, as they discussed with their grandchildren their 3D creations, tried to help them with SketchUp™ at home and attended their workshop and classroom presentations. One grandmother, sought help with SketchUp™ for her grandson at home, "In fact we emailed Steve [program moderator] a couple of times, 'now how do you do this' and he was very prompt, he emailed us right back with instructions." Other times the mentor/teacher role was reversed and the grandchild helped the grandparent with computer technology, "I will call him up and say, I need your help and he says Grandma, all you have to do is this and this." Another grandmother whose grandson was teaching her how to use the SketchUp™ program said, "I don't know how to do this, buddy. But he said, I'll show you Grandma, I can help you and he did." This 'tech-teaching' had an upward flow from the grandchild to the grandparent, emphasizing the child's strengths and confidence with computer skills and expanding the grandparent/grandchild interaction and communication of a shared interest.

Peer support through focus groups

Interaction and communication also increased between the grandparents of the grandchildren with ASD. The focus group discussions provided these grandparents the opportunity to share their joys, their fears, their concerns, and experiences with other grandparents with grandchildren on the spectrum. Meeting other grandparents with children with ASD was comforting and reassuring. They understood each other's emotional roller coaster, the difficulties their children and grandchildren experienced within society and they understood, accepted and celebrated each other's grandchildren's experience and growth from being in this SketchUp™ program.

Figure 1. Key Theme: Reframing Expectations

Figure 2. Key Theme: Building Communication Bridges through Share Interests

DISCUSSION

Our findings emphasize the value of the grandparent-grandchild relationship and the effects of the grandparents perceived success for their grandchildren with ASD. Based on their perceptions of their grandsons' success in their participation in the SketchUp™ workshops; the grandparents acquired a more optimistic vision for the grandchildren's future. The family systems theory was substantiated in the study and the merit of peer support was accentuated in the grandparent focus groups.

Changes in demographics have resulted in increased opportunities and needs for interaction, support, and mutual influence across more than just two generations (Bengtson & Oyama, 2007). Changes in fertility patterns and longevity have resulted in more living grandparents with proportionately fewer grandchildren on whom to focus their attention. The intergenerational relationship between a grandparent and a grandchild has been described as bidirectional, with benefits for both. Mutual benefits for the grandparents and their grandchildren included in this study were recognized. For the grandparents, the relationships and interactions with their grandchildren provided them a sense of purpose and a feeling of being valued (Thiele & Whelan, 2008). Many grandparents take great pride in their grandchildren (Harwood & Lin, 2000). These grandparents celebrated the social and technological success they witnessed from their grandson's participation in the SketchUp™ workshops. Grandparents identified making friends and gaining both social and computer skills as areas in which their grandsons

improved. They also perceived their grandchildren as having improved confidence and self esteem from their ability to use SketchUp™ and explain their designs. Several studies indicate that grandparents derive enjoyment and companionship from their interactions with grandchildren (Barranti, 1985; Cunningham-Burley, 1986a; Thomas 1990a).

The supportive grandparents in this study attended their grandchildren's events, served as confidants, companions, friends and mentors, and provided instrumental assistance and emotional support to their grandson with ASD and his family. Yet, all families are different and other grandparents may be less involved or uninvolved with their grandchildren for personal reasons, including their health, age, culture, family relationship difficulties or lack of resources. Proximity, understanding and knowledge about ASD and the grandchild's behavior may also factor in to grandparent involvement and warrants further research to understand the reasons some grandparents are actively engaged in these children's lives and others less involved.

The findings of the study supported the family systems theory, that the quality and quantity of involvement of the grandparents in the life of their grandchild was contingent on the family network relationships. The roles these grandparents of grandchildren with ASD assumed, included adapting to the grandchildren's limited social, and communication skills and their behavior changes, serving as supportive family members and contributing to the family function as a whole. The grandparents functioned within the rules and boundaries established by their grandchildren's parents and formed strong emotional family connections. The reciprocal interactions between the grandparents and grandchildren promoted the cohesiveness and cooperation of the family unity. Congruous with Katz and Kessel's (2002) results, our findings support the idea that grandparents of grandchildren with developmental

disabilities provide instrumental support, as well as important emotional support through their acceptance and direct involvement with the grandchild.

Children with developmental disabilities may benefit from their relationship with grandparents who believe in their potential to improve and who focus on the positive aspects of development, rather than on the limitations of the disability (Levitt, Weber, & Guacci, 1993). Their grandchildren's many previous failures in community and leisure activities were verbalized by the grandparents. They voiced their grandchild's enthusiasm and enjoyment of the SketchUp™ program. The grandparents recognized their grandchildren's affinity for computer skills and acknowledged individual talents their grandchildren possessed. Grandparents perceived that the SketchUp™ program highlighted their grandson's computer strengths and was something at which their grandsons could excel. Focusing on strengths rather than limitations affects the attitudes and beliefs of family members, creating greater hope about the child's ability to function well and contributing to the development of strong emotional bonds (Cosden, Koegel, Koegel, Greenwell & Klein, 2006). The grandparents commented on their grandson's successes and increased confidence from their participation, and they formed a more positive vision for their grandchild's academic and occupational future. They expressed hope and optimism for their grandchild's future from the social engagement and computer skills the children experienced through the SketchUp™ workshops. Grandparents' perspectives on computer activities shifted across the two focus groups. Initially they felt their grandchildren spent too much time playing computer games and they constantly tried to distract them with other activities. In the second focus group discussion the grandparents articulated the potential occupational benefits from constructive computer activity. The grandparents also expressed the desire to improve their own computer

skills. The upward flow of 'tech-teaching', provided by the grandchildren to their grandparents, emphasized the child's competence and confidence with computer technology and afforded the grandparents the opportunity to engage with their grandchildren through this shared interest.

Interventions designed for children with ASD tend to focus on their social, cognitive, and behavioral deficits. A strength based approach was the intent of the SketchUp™ workshops. Understanding the strengths of an individual with ASD is equally as important as understanding their limitations. Coyne and Fullerton (2004) stated, "Incorporating strengths into activities can lead to a decrease and /or elimination of challenging behaviors and more positive interactions" (p.12). Grandparents commented on their grandson's increased confidence and self-esteem from their SketchUp™ interactions and skills acquired. Grandparents perceived that communication and interpersonal relationships, a common impairment for children with ASD, were enhanced through their participation in the SketchUp™ workshops. The ability to sustain and develop an area of interest is a real strength for children with ASD that can lead to accomplishment and satisfaction.

The focus groups afforded the grandparents interaction and communication with other grandparents of grandchildren with ASD. Davison, Pennebaker, and Dickerson (2000) found that the people who most often sought out support were individuals experiencing stigmatizing illness who may feel social anxiety and alienation from their usual support network. Having a grandchild with ASD may create barriers of communication about their grandchildren with other grandparents. For some, having a grandchild with ASD may feel isolating and stigmatizing. Other grandparents may not understand ASD and make judgments or criticize observed behaviors. Although these grandparents had not actively sought out this

peer support, they seemed to enjoy the opportunity to discuss their family's experiences with a child with ASD, their fears, concerns and worries for the future. They recognized and validated one another's challenges and likewise celebrated and rejoiced in their grandchildren's accomplishments. Our observations of the benefits of peer to peer support that grandparents experienced in the focus groups is supported by Woodbridge, Buys and Miller (2009) who concluded that grandparents of a grandchild with a disability, as well as parents, need support to help them process their emotions and to develop ongoing strategies to cope with their situation.

Strengths and Limitations

This study has several limitations. The focus groups contained only a small number of participants. Participant bias and researcher bias cannot be eliminated. Although the focus groups had a set of guiding questions both participant and researcher bias may have directed the discussions. We do not know to what degree the focus group participants are representative of grandparents of grandchildren with ASD because all who participated, were actively engaged with their grandchildren who attended the SketchUp™ workshops. It is possible that we missed important data obtainable only from grandparents who did not participate. Understandably the criticism that the convenience sample and limited number of participants is not representative of the population of grandparents of grandchildren with ASD is well recognized and we cannot generalize these findings. While valuable in providing some insight into how grandparents feel about their grandchild with ASD experiences, it is difficult to generalize from this research.

However, this preliminary study did explore an important and previously underexplored subject, and extended our knowledge by providing a detailed investigation from the grandparents' perspective of their grandchild with ASD's experiences of being involved in the 3D SketchUp™ workshops. Further research is needed to explore grandparents' motivations and barriers to participation and intergenerational communication in families with children diagnosed with ASD. Furthermore, repetitive studies need to be conducted to validate the findings of this study.

CONCLUSION

The subject of this study is both timely and meaningful given the increase in ASD among the grandchildren of today's grandparents and the focus of technology in these children's lives. Recognizing that life in families with a child with ASD is constantly changing and challenging, this study sought to capture from the grandparents' perspective the outcome of their grandchild's participation in a preliminary workshop session using the Google SketchUp™ software. The purpose of this study was twofold, to investigate this under acknowledged population, grandparents in families of children with ASD, and to identify the meaning grandparents attributed to their grandchildren's participation in SketchUp™ workshops. This study sought to give voice to and share the views of these highly engaged grandparents of grandchildren with ASD.

The grandparents believed that their grandchildren had made genuine friendships in the workshops, they expressed that their grandchildren thoroughly enjoyed using the SketchUp™ program, and that they themselves could envision a brighter future for their grandchildren. Grandparents shared that they had reframed their own ideas about the value of computer technology and recognize its benefits for their grandchildren with ASD. The SketchUp™ workshops represented a successful program based on the strengths of the children with ASD. It also afforded the grandparents a new opportunity to engage with grandchildren and other grandparents who participated in the study. Rather than converging over the disease as an unfortunate commonality in a traditional

support group setting, this program and study provided a positive collection of interactions and associations for greater understanding of strengths and peer group supports; giving the grandparents a new opportunity to engage with their grandchildren and with other grandparents of grandchildren on the autism spectrum.

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